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Prolonged grief disorder in section II of DSM-5: a commentary

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Dear Editor,

The American Psychiatric Association (APA) has proposed to change the position of disturbed grief in DSM-5, replacing criteria for Persistent Complex Bereavement Disorder (PCBD), currently in Section III (American Psychiatric Association, 2013), for criteria for Prolonged Grief Disorder, to be moved into Section II (APA, 2020). This novel DSM diagnosis shares its name with grieving disorders put forth by Prigerson et al. (2009), by Maercker et al. (2013), and included in ICD-11 (World Health Organization, 2018). However, the criteria do not overlap completely. DSM-5 PGD is present when, after the death of someone close at least 12 months earlier (Criterion A), a person experiences intense yearning or preoccupation (Criterion B), plus at least 3 of 8 symptoms of identity disruption, disbelief, avoidance, emotional pain, difficulties moving on, numbness, a sense that life is meaningless, and loneliness (Criterion C) for at least one month, that cause distress or disability (Criterion D), exceed cultural and contextual norms (Criterion E), and are not better explained by another mental disorder (Criterion F). DSM-5 PGD represents the sixth candidate criteria-set for disordered grief, next to PCBD, three prior proposals for PGD, and Shear et al.'s (2011) criteria for Complicated Grief (CG) (Boelen & Lenferink, 2020).

In our view, it is a welcome step if criteria for DSM-5 PGD are added to Section II, as disordered grief would then be recognized as a formal DSM diagnosis. It would be a logical consequence of research demonstrating that different combinations of putative PGD symptoms¹ meet the definition of a mental disorder (e.g., Stein et al., 2010). The symptoms form a recognizable set of symptoms that can be reliably identified (Lichtenthal et al., 2018). Factor, latent class, latent trajectory, and network analyses have shown that these symptoms are distinct from symptoms of depression, posttraumatic stress, and

generalized anxiety (e.g., Djelantik, Robinaugh, Kleber, Smid, & Boelen, 2020; Lenferink, Nickerson, de Keijser, Smid, & Boelen, 2020) and incrementally predict distress and disability beyond these neighbouring syndromes (Prigerson et al., 2009). Studies have shown that trajectories of resilience and recovery are much more prevalent than trajectories of chronic PGD symptomatology (Nielsen, Carlsen, Neergaard, Bidstrup, & Guldin, 2019), indicating that PGD is not 'an expectable response to a common stressor' (cf. Stein et al., 2010, p. 1762). Moreover, there is evidence that PGD symptoms have distinct neurobiological correlates (Bryant, Andrew, & Korgaonkar, *in press*). The clinical utility of PGD symptoms is supported by evidence that these symptoms are more successfully treated using grief-specific rather than other (e.g., depression-focused) interventions (e.g., Shear et al., 2014).

In clinical care we, and many clinicians with us, commonly see that deaths of loved ones precipitate persistent pain that exacerbates rather than abates as time goes by, that, in patients confronted with traumatic losses (e.g., to homicide, traffic accidents), separation distress (yearning/longing or preoccupation) overshadows traumatic distress (including intrusive symptoms and alterations in arousal and reactivity), and that bereaved patients report difficulties engaging in usual activities that resemble symptoms seen in depression but might better be conceptualized as inhibition of the exploratory system driven by separation distress.

So, we welcome the inclusion of PGD in DSM-5's Section II. We do so as researchers, considering that this will stimulate research on the prevalence and maintaining mechanisms of, and preventive and curative care for disturbed grief. This is crucial because this research is still limited, compared with research on other common mental health disorders, and insufficiently generalizable, due to the many different ways

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The American Psychiatric Association (APA) has proposed, including Prolonged Grief Disorder, as a novel disorder in Section II. This is a welcome step, helping researchers and clinicians. We also have some concerns about this proposal, that are articulated in this letter.

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disordered grief has been defined. And we welcome this inclusion in Section II as clinicians, considering that an established DSM-5 disorder fosters the identification of, communication about, and the provision and reimbursement of targeted care for the significant minority of bereaved people in need of help following loss. We recognize that establishing PGD as a DSM diagnosis also comes with inevitable drawbacks resulting from misconceptions about mental illness, such as stigmatization of people diagnosed with PGD (e.g., Eisma, 2018), but we believe that these disadvantages are outweighed by the advantages of this development.

All that notwithstanding, we have some concerns about the DSM-5 PGD proposal, that we hope can be allayed in the process towards the appearance of the revised DSM-5. First, we think that PGD should be placed in the DSM-5 chapter about trauma and stressor-related disorders. The current proposal is for PGD to be included in the chapter on depressive disorders. This is puzzling, since clinicians will naturally be inclined to position bereavement as a stressful event – the possible mental health consequences of which are closer to symptoms seen in other event-related disorders (Dalglish & Power, 2004) than to (not exclusively event-related) dysregulation of positive and negative affect characterizing depressive disorders. Notably, in DSM-5, PCBD is, in fact, classified as ‘other specified trauma and stressor related disorder’ (and not as ‘other specified depressive disorder’; American Psychiatric Association, 2013) and in ICD-11, PGD is one of the ‘disorders specifically associated with stress’ (World Health Organization, 2018). Furthermore, across recent latent class analyses, PGD symptoms are consistently more likely comorbid with traumatic stress, than with depressive symptoms (e.g., Djelantik et al., 2020).

Second, the 12 months timing criterion should, in our view, be reconsidered taking into account evidence that elevated PGD symptoms in the first few months strongly predict persistent disabling grief beyond this period (Boelen & Lenferink, 2019), that people following chronic grief trajectories mostly show signs of elevated grief before the first anniversary of the death (Nielsen et al., 2019), and that elevated PGD symptoms predict later traumatic stress and depression more strongly than vice versa (Lenferink, Nickerson, de Keijser, Smid, & Boelen, 2019; O’Connor, Nickerson, Aderka, & Bryant, 2015), despite the fact that PTSD and depression can be diagnosed earlier after the loss than PGD. Moreover, elevated PGD symptoms beyond 6 months reliably identify bereaved individuals at risk of long-term dysfunction (Prigerson et al., 2009) and ICD-11 correspondingly adopted this timing criterion. We think there is sufficient evidence to change the timing criterion for DSM-5 PGD into > 6 months. We also see clinical arguments to do so: it does not make much sense to give other diagnoses to bereaved patients applying for help for disabling grief in the second

half year of bereavement (let alone to withhold care if no other diagnoses apply) knowing that, in most instances, this severe grief does not naturally abate (e.g., Lenferink et al., 2020; Sveen, Bergh Johannesson, Cernvall, & Arnberg, 2018).

Third, the proposed F criterion states that ‘The symptoms are not better explained by another mental disorder.’ This broad description deviates from similar criteria in DSM-5 for PTSD and major depressive disorder, in which alternative explanations for the symptoms are more specifically defined (e.g., for PTSD: ‘*The disturbance is not attributable to the physiological effects of a substance (e.g., medication, alcohol) or another medical condition*’). Our concern is that this broad F criterion will lead to PGD being easily mistaken for some other (as yet better known) disorder and, consequently, remain underdiagnosed and treated with less effective interventions. To avoid this, we propose to specify the F criterion, similar to corresponding criteria for PTSD and major depressive disorder.

Fourth, we see some problems with the formulation of Criterion B. This criterion actually includes two symptoms (‘yearning/longing or preoccupation’), with very different prevalence rates (e.g., 61.7% for ‘yearning/longing’ vs. 25.7% for ‘preoccupation’, in Boelen, Lenferink, Nickerson, & Smid, 2018), indicating that they represent different phenomena rather two expressions of one phenomenon. PGD as per ICD-11 also combines separation distress and preoccupation in one single criterion. PGD as per Prigerson et al. (2009) only includes ‘yearning’. In the PCBD criteria, ‘yearning’ and ‘preoccupation’ are two separate symptoms. Considering that yearning/longing and preoccupation are both valid markers of disordered grief (e.g., Boelen & Hooijink, 2009) we propose to consider including both symptoms as B1 and B2 criteria, adding a diagnostic rule that at least one of these symptoms must be present.

Fifth, we are concerned about the proposed symptoms not all being tapped by the most commonly internationally used and well-validated measures of disturbed grief, including the Inventory of Complicated Grief (ICG, Prigerson et al., 1995), the revised ICG (ICG-R, Prigerson & Jacobs, 2001), and the PG-13 (Prigerson et al., 2009). For instance, ‘identity disruption’ is not captured by the ICG, ‘difficulties moving on’ is not captured by the ICG and ICG-R, and ‘preoccupation’, ‘loneliness’, and ‘disbelief’ are not included in the PG-13. So, with the entrance of PGD in DSM-5’s Section II, a set is proposed that is largely but not completely captured by extant measures; and data on disordered grief gathered to date largely but not completely map onto these criteria. This disturbs the continuity of assessment of PGD in research and practice. It is not easy to dispel these concerns. But – to the extent that such is justified by empirical evidence – some revisions in wording of some of the symptoms may be considered to align the criteria with existing measures

Sixth, further concerns are connected with the proposed diagnostic algorithm. The good thing is that this algorithm, with a cut off of 3/8 symptoms for Criterion C, yields only 219 symptom combinations, which is much less compared to, e.g., PCBD and ICD-11 PGD (37,650 and 3,069 combinations, respectively). Also, preliminary evidence shows that the diagnostic agreement between DSM-5 PGD and other candidate criteria-sets is substantial (Boelen & Lenferink, 2020). However, our worry is related to the fact that the chosen diagnostic algorithm has significant consequences for the prevalence rate, heterogeneity, and diagnostic agreement with other grief disorders. For example, the lenient PGD ICD-11 algorithm has been shown to yield two- to threefold higher prevalence rates compared to PCBD criteria (e.g., Boelen et al., 2018). So, although 'the data strongly supported a cut-off of 3/8 symptoms for Criterion C' (APA, 2020), research is needed to substantiate the predictive validity, as well as the sensitivity and specificity, of this 3/8 threshold – considering the impact of this threshold on disorder prevalence. It would be worthwhile to evaluate different symptom thresholds in conjunction with different timing criteria (e.g., PGD with a time criterion of > 6 months and a 4/8 Criterion C threshold) relative to the currently proposed >12 months and 3/8 symptom threshold.

Taken together, we firmly support APA's proposal to move disordered grief as a formal diagnosis to Section II of the DSM-5. There are some caveats with this move, that we hope can be addressed in fruitful future scientific and clinical exchanges.

Note

1. For reading ease, we use the term 'PGD symptoms' to refer to different grief disorders proposed over the years, that have been assessed with different measurements instruments.

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